APLI: Learning Experience at Pallium India
November 2017 – February 2018
Dr Delamy Keall – Palliative Medicine Advanced Trainee

"We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, to love… and then we return home." Aboriginal proverb

As part of my Palliative Medicine Advanced Training programme, I arranged to spend three months observing and working at Pallium India. I chose this elective attachment at the end of my three years of specialist training to deliberately push myself out of my comfort zone. My hope was to reconnect with the essence of palliative care in a resource-poor working environment. I also wanted to gain some understanding of how it felt to be part of a cultural minority and to experience a language barrier.

Pallium India is a palliative care organisation based at Arumana Hospital in Trivandrum city in the southern state of Kerala. It was founded and is chaired by Dr Rajagopal, considered by many to be the 'father of palliative care in India'. Pallium India runs home visit programs in and around Trivandrum, an inpatient unit, and outpatient clinics, some in collaboration with different hospitals in Trivandrum. Pallium has approximately two thousand registered community patients living within a 30-kilometre radius of Arumana Hospital. The inpatient ward has 10 beds. Other services include bereavement support groups, Vocational Rehabilitation Program for spinal injury patients and families, and education support of children whose parents are under treatment by Pallium India. Services and medications to patients are provided free of cost and expenses are met by donations. Pallium India also has a well-developed training department, Trivandrum Institute of Palliative Sciences, which provides training in palliative care and pain management for health professionals and volunteers from South Asia.

To Observe

During my first weeks I took part in ward rounds, accompanied home visit teams and sat in on teaching programmes. The medical staff spoke with patients in the local language, Malayalam and sometimes the staff would translate for me in English. The Pallium staff found my spoken English very difficult to understand so I learnt to rely on my observational skills and reading the clinical notes which were written in English. I learned so much simply by keeping quiet and not offering my opinion! I saw that there were different ways to deliver good palliative care. For example, acceptable pain relief for most patients can be provided with short acting morphine tablets given every four hours with a double dose at bedtime. I was humbled by the communication skills of staff who gave patients and their families their full and unhurried attention.

I noticed the influence that culture has on the application of knowledge. Despite the medical staff being taught a universal palliative medicine curriculum I noted many differences between the way care was delivered at Pallium compared to NZ. Most in-patients had some of their medications delivered through an intravenous line which often included antibiotics and intravenous fluids. I visited patients with advanced dementia or strokes being lovingly sustained at home with a nasogastric tube for feeding. Far less investigations were carried out to find correctable causes for symptoms, usually due to the financial cost of investigations. Collusion between the patient, family and medical staff about withholding the diagnosis and prognosis was common but gentle efforts were usually made to break the collusion. Discussions about prognosis were difficult for both the doctor and family due to concern about the distress this may cause the patient. Questions about a patient's spirituality were minimal and not considered a responsibility of the hospice team, despite religion being a central part of Indian culture.

To Learn

The training division of Pallium India, runs several different training programmes throughout the year with a focus on improving the awareness and expertise of healthcare and allied healthcare professionals. Doctors and nurses came from all over India and neighbouring countries to complete a ten-day foundation course or six-week comprehensive course in palliative care. I offered to contribute to the teaching programme which was met with some hesitation regarding my NZ accent despite all teaching being delivered in English. However, the students were well able to understand me if my teaching content was supported with PowerPoint slides for them to read. I was asked to do more teaching as the weeks passed. I helped to deliver Pallium's first distance-learning Foundation Course using the ECHO (Extension for Community Healthcare Outcomes) Zoom learning platform. It was a joy to see the doctors and nurses develop in their confidence around prescribing opioids and having difficult conversations. Many of them finished their course with the vision and skills to become leaders in the expansion of palliative care services in India.

At the end of my time in India I attended the annual International Conference of Indian Association of Palliative Care (IAPCON 2018) in New Delhi. The theme was Create, Collaborate and Communicate which acknowledges the growing recognition of the importance of palliative care in India. This was a three-day feast of inspiration and learning from clinicians, researchers and world leaders regarding global and Indian palliative care topics. The future of palliative care in India is in good hands with a growing number of committed and trained workers in the field. Next year's IAPCON 2019 is in Kochin in February and international visitors are encouraged to attend and contribute to this conference.

I have been deeply touched by the clinicians (nurses and doctors) who deliver such compassionate care and work so hard in a physically demanding work environment. I am humbled by their dedication to the mission of educating their community and health professionals about the philosophy of palliative care and how to deliver it well. I am inspired by the quality of care that can be provided in a basic hospital building with no hot water, a limited choice of opioids, home-made wound dressings and limited IT infrastructure.

To Grow

Moving out of my comfort zone provided an environment for my personal and professional growth. Every day I found myself in situations out of my control - culture, food, language, responsibility, travel, expectations, sickness, mosquitos, heat, dehydration. My faith deepened as I trusted in my God to sustain, provide for, strengthen and protect me. For many weeks I lived alone in an apartment which allowed me to find an inner peace that has remained with me as I return to the busyness of life back in New Zealand.

My definition of palliative care has been enlarged through listening to Dr Rajagopal teach Indian doctors about the "palliative approach". My previous definition of "care for those with a life-threatening illness", has changed to "care for those with serious health-related suffering", as per the recent Lancet Commission on Palliative Care and Pain Relief, 2017. As a palliative care doctor, I will now be asking myself: Does the person have serious health-related suffering? If so, is anybody addressing that suffering? If not, then what can I do to reduce that suffering? These questions should be asked of any patient requiring medical intervention to reduce their suffering, at any stage of their disease journey.

After three months of quietly observing and with the support of Professor Ann Broderick a visiting palliative medicine specialist from the USA, I had the opportunity to suggest some areas of development for the work at Pallium. We mentored the doctors as they started to prescribe methadone which had recently become available in India for pain management. We encouraged the inpatient team to start a daily inter-disciplinary meeting before each morning ward round. I designed a community drug chart to improve medication reconciliation and reduce the workload on prescribers. I continue to work with the medical director to establish a weekly doctors peer review meeting.

To Love

Dr Rajagopal and his team demonstrated daily that to listen is to love. The doctors, nurses and social workers listened to their patients, families, staff and students and adjusted their care to suit each individual. The teaching at Pallium included a strong emphasis on compassionate and effective communication skills. I have been reminded to lean in to my patient, of the importance of being fully present and to expect answers to emerge from the silences.

Pallium's vision is "An India in which palliative care is integrated in all health care so that every person has access to effective pain relief and quality palliative care along with disease-specific treatment and across the continuum of care". This vision is motivating for the many volunteers who contribute to the work of Pallium and who do so for love. Each volunteer who donates their time and skill to the cause is as valued as any other staff member. A weekly team meeting is held for all paid staff and volunteers where the work and direction of Pallium is presented by the senior leaders and discussed by all. This meeting helps cement the caring culture of the organisation and provides an opportunity to celebrate the work at hand.

We Return Home

My planned flight home was abruptly terminated at Delhi airport. I had accidentally overstayed my 90-day tourist visa by eight days and was ordered to remain in India to work my way through the Indian Immigration Department process as an overstayer. This took a week to sort out along with additional hotel and air ticket expenses. I include my mistake as a warning for others planning to visit India on a tourist visa. Unless you want to experience being at the mercy of Indian government bureaucracy, do not stay past the specified time on your visa!

Despite the many challenges I faced, I returned home a changed and happier person due to my Indian palliative care experience. I have a fresh appreciation of my New Zealand work environment and everything I have available to help patients and families. I feel a future responsibility to share my knowledge and resources with palliative care colleagues in developing countries. I can understand the difficulty of being in a strange culture where everyone speaks another language. I have grasped the Pallium way of moving towards all serious health related suffering:

We refuse to look the other way.
We choose to hear the cry.
And to do what we can.

I am grateful for my APLI mentors – Dr Anil Tandon who worked with the Royal Australasian College of Physicians to have Pallium accredited as a training site, and Dr Odette Spruyt who Skype-talked me through my cultural challenges and encouraged me in my teaching efforts.